

**Aspergers Syndrome Support Group
for Families in Macarthur**

October 2008 News Sheet

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Support Meetings

School holidays played a major role it think in reducing the numbers of parents able to get along to our two support meetings in October. In fact for a while I thought no one was showing up on the Wednesday except for a lady who mistakenly sat down at our table. It turned out she was there to meet a friend but did had have an adult son with aspergers who was involved with Autism NSW and other services a number of years ago. It is a small world isn't it. A parent did turn up and we had a good talk about her daughter going into school next year and how she could help her in this important transition in her life.

On Thursday the boys outnumbered the girls for a change with a new dad coming along and Jonathan providing us all with a laugh and first hand knowledge on a few of the things we were talking about – thanks Jonathan. There was plenty of positive stories being told and how families handled the diagnosis of their child and services they accessed.

See it does pay to turn up at meetings to get ideas, learn about local services and just have a laugh and meet others families. Some of the information talked about or handed out does not find its way into this newsletter due to space and my memory.

There are only two more meetings left this year and then you will have to wait until February '09!!!

November Meetings

I encourage families to come along to our meetings – we all need you there to share your experiences, ideas and support

- **Second Wednesday 12th November** 10 am at The Coffee Club Café at Macarthur Square, next to Border Books, down stairs and outside where all the new coffee shops etc are. An opportunity to have chat over a cuppa of your choice.
- **Second Thursday 13th November** 7pm at the Harrington Park Community Centre Fairwater Dr next to the shopping centre. For those who work or are busy during the day to meet other families and share their experiences and ideas.

Library Books

The books in our small library remain popular with families; however it is really important that they get returned ASAP so that others can access them. It does cost money to purchase them – up to \$100 in one instance, something the Co-operative does so families do not have to pay for them.

So please bring them back – I am happy to come and collect them, no questions asked!!

Taking about books there is a new one out called “All dogs have ADHD” which follows the theme of the popular book titled “All cats have aspergers”. I have seen it at local bookstores for \$25 a copy.

I had a snoop through the Narellan Library the other day and borrowed a couple of books to read:

Helping the Child with Learning Difficulties find Social Success by Richard Lavoie

Dyspraxia by Geoff Brooks

Bullies Bigmouths and so called friends by J Alexander – aimed at school aged children

They have been returned so they could be available for you to borrow.

Remember when searching for books look at the issue at hand – like behaviour or social skills, not just at aspergers. Libraries put most of the books I find in the Health section - likewise most for bookstores. Check out Sinclair's newsagency in Camden and Border Books at Macarthur Square

Has your child been recently diagnosed with ASD?

The University of NSW's Social Policy Research centre would like to talk with parents of recently diagnosed children to find out their experiences with treatment and therapies. Recent diagnosis means **anytime in the last two years**'. They want to know:

- who has been helpful in deciding which therapist to use?
- what information sources have been helpful to you?
- What formal or informal support have you had?

And they will provide you with a \$30 Coles Myer gift voucher for your time. They have not been able to talk with people from the South West Sydney region so it is an opportunity to help with the research and tell them about issues in our region.

Research like this is important as it can influence government policy makers and can lead to funding of organisations like the Co-operative and support groups like ours.

If you are able to spare an hour call Marianne on 9385 6364 or mrjajkovic@unsw.edu.au or Brooke on b.dinning@unsw.edu.au All information will be treated in the strictest confidence.

Rainman is everywhere

A number of shows have appeared on TV lately including Rainman goes to RockQuiz (SBS) and The Rainman Twins (Nine). There was also another segment on Catalyst (ABC) talking about the difference between Autism and Aspergers. If you caught any of them I hope that they increased your understanding of the characteristics of people on the spectrum and importantly the positive abilities of people who have aspergers.

The Rainman Twins documentary also showed how change of a person's environment can have a huge impact upon people especially if it includes the person who is their main carer (both of the twin's parents died, then their younger sister who had become their carer and under whom they had really blossomed)

I did tape two of the shows and you can borrow my effort that includes advert's and stuff I taped over. Will have it at the Thursday night meeting and may show it if people feel they want to see it.

Helping children with Autism

Another section of this initiative is being rolled out – workshops and information sessions for parents/carers of school aged students on the autism spectrum. There is a two day workshop/information session scheduled for February 2009 at Ingleburn. People can get more information by calling 1300 881 971 or by visiting www.autismtraining.com.au

I have provided those families without access to the internet with a "glossy brochure" that outlines what the workshops etc are about. If you do not get one give me a call and I can provide a brochure (details it contains is on the web site)

I encourage people with school aged children to attend these workshops or link to the online training and materials offered to support you.

The parent/carer workshops will supplement the ones being run for teachers and school staff. **Perhaps you can advocate for your school to look at the website to find out how they can benefit from the professional development training being provided.**

Autism Spectrum Australia (Aspect) News

Have you taken up this opportunity yet?

Social Clubs for boys and girls 8-18 years are being established across NSW under funding from the State Government. Information on this new program has been sent out to all families in the Support Group, however to get one happening in the Macarthur region people need to make an application to Aspect as soon as possible. Clubs will only be set up in areas of most need – **that is where parents tell Aspect that they need it.** You can get an application form off the Aspect web site www.autismspectrum.org.au or by contacting the Co-operative.

Fathers and Grandfathers Workshop

Wednesday 12th November 7 pm to 9.15 pm at Club Burwood 97 Burwood rd (Cnr George St) Burwood.

An all too-rare opportunity for fathers and other male carers of children with ASD to come together. The night will talk about Communication across the spectrum - 2 way strategies and perceptions facilitated by the behaviour Intervention Service of Autism Spectrum Australia.

Refreshments (substantial they say!!) available from 6.15 pm –for further information contact Pauline on 8977 8335 or phunterknight@autismspectrum.org.au

Off the web

A couple of sites that I found interesting and worth a visit when you are surfing the web

www.carersaustralia.com.au site launched as part of carers Week that was celebrated last week. Links to information on caring and what you are entitled to.

www.familycare.org.au a site established by a parent of a young man with a disability who is now assisting others deal with life long caring strategies and how to plan for the future. Terry Ryan has provided training to a number of local families through Macarthur District Temporary Care who are looking at running the courses again early next year

Let me know of any sites you found useful and I can include them in future news sheets.

Writing down your story

Over the past weeks I have been assisting a local family regarding funding and options for an accessible vehicle for her foster son who uses a wheelchair to get around. In the conversations I have had with her it prompted me to remind her to write her story down.

Why? Well we all forget the small instances and details that make up our busy and constantly changing lives and when dealing with governments, services and advocating to people like your local member it is important that they get a real good picture of what has happened in your life and that of your child. Facts dates instances – including positive events, can be presented in a coherent manner without having to come up with them on the spot or the old “I will get back to you on that” that often never happens.

Many families have kept a diary full of daily antidotes that they can look back on and see where they were and where they are now. It is surprising to see what progress can take place over time.

I now local Members of Parliament are happy to assist families but are very busy people – so giving them a concise story of your situation can help them help you.

And it means you do not have to keep telling it over and over. Terry Ryan came up with what he called his son’s Family Care Plan that included all relevant details and his son’s aspirations that he gives to carers, services and agencies that he comes into contact with. It also lets other family members know how he wishes his son to be cared for if anything should happen to him.

Sue Larkey

I have received Sue’s latest email newsletter that is full of information, ideas, and resources that can be purchased through her. Or I know families who look at the resources available and have gone out and brought similar items at the local \$2 shop. That’s OK and is a way of adapting other people’s ideas to your own situation – and wallet.

Sue has developed up a Profile for Individual Student sheet what can be used for programming for students with Autism Spectrum Disorder. Would be a great resource to give to your child’s teacher or school. Available on line at www.suelarkey.com or by contacting me for a copy.

Glenda Benton Dance Academy

If your child is interested in dancing, having heaps of fun and meeting other children why not look at being part of the program provided through this Dance Academy for children who have a disability. This program runs out of their studios at Chipping Norton and has performed at many local functions including *Kites for Kids* and *Everyone can Dance*

Give them a call on 9527 9400 or 0408 160 479 or look up www.glendabentonacademy.com

Look forward to seeing you at a support meeting soon.

Until next time **Bob Lester**

4648 1593 or 0400 481 520 or email coordinator@fip.org.au

Check out www.fip.org.au for more information on aspergers and other disability related issues.